

more stories and ideas

Jumping the gap more stories and ideas

# Jumping the gap more stories and ideas



A Project of the Community Involvement Council

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# Who we are

The Community Involvement Council is an active group made up of representatives from human services agencies across several counties in southwestern Ontario. Our monthly meetings provide a forum for sharing ideas and resources.

In the book, Her shoes are brown and other stories, the Council recognized the importance of listening to and celebrating people's stories. There was also a recognition that gaps still exist between philosophy and action. Many people shared their stories, thoughts and ideas on ways to bridge the gaps. These are compiled in this book.

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You came through again! Jumping the gap - more stories and ideas grew from our struggles. Thanks Helen Watson, Sara Thorne, Tricia Morris, Bill Gow, and Bud Carter. To Frank Moore and Marty Graf, on the sidelines, thanks for being there.

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Thanks!

Chris Hicks Barbara Leavitt Diane Peacock

Dedicated to those who take time to reflect release and rejoice

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# leaps of faith

It is hard to remember how one got from there to here. The stories in *Her shoes* are brown and other stories remind us all that the journey is one of exploration, joy and heartache. Rarely do things go according to plan, and rarely does the result look like the initial intent.

Life is a broken landscape of plateaus and chasms. There is no map or set itinerary. Progress means jumping the gaps, or finding the bridges to the next plateau. Some plateaus have many people, some only a few, and some none at all. Our desire to explore leads us to find ways to reach those groups of people, or to go where no one is. Sometimes, we can jump easily from one plateau to the next. Sometimes, there does not appear to be a way to get across. The gap is too wide. But we can move on to meet new people, to see new places, to challenge ourselves.

Jumping the gap - more stories and ideas shows us some of the ways people are exploring. It tells of jumps made safely, and of leaps made in faith. Faith that others will help. Faith that a bridge exists, though unseen. Faith that we have the courage within us to find the bridge. And faith that on arrival, we will have time to rest, to heal and to celebrate.

Each of these jumps is frightening. Even if we know we can make it, there is no guarantee that we will be accepted. When we cannot see the bridge over the gaps, the jump is terrifying.

The wisdom found in *Her shoes are brown* and *Jumping the gap* tells us the bridge is there. It is found in the love and trust of others. It is found in the love and trust of ourselves. It is found in the profound understanding that we are all human, and that we are all in this together.

The Stories Advisory Committee Community Involvement Council

# notes to the reader

In the book, Her shoes are brown and other stories, people shared both their struggles and successes. Lots of us were inspired, or re-inspired, to help people become more actively involved in their hometowns. Yet often, something stops many of us. There is a gap that separates philosophy and action, good intentions and actually following through. We all seem to recognize the "right" way of doing things. The philosophies which encourage us to support each other in positive, natural and enhancing ways, have us all nodding our heads in complete agreement. We believe it. So what is stopping us from putting our beliefs into action? What is that space between the rhetoric and reality? Is there a darker side to the idea that all people can contribute? How are we measuring up in promoting growth and change? Can we be personally involved in change? Why do we second-guess what we know to be true? Why are we afraid to act?

We discovered, in compiling ideas for this book, many people in Ontario were willing to talk about their personal struggles with those gaps. Our gaps included personal fears such as anxiety about taking action, and/or external forces such as rules of the system. Gaps came in different sizes, were cloaked in different forms, and were experienced by people regardless of position or life experience. We can become defensive and blame staff for not following through, parents for being overprotective, individuals for lack of motivation, managers for the rules, or others for not welcoming people. While these gaps seem too difficult, there are bridges. Many stories in this book celebrate crossing those bridges.

#### Notes

Facing fears and limitations is often the first step taken by individuals who are determined to move ahead. They have discovered the simple truth of looking within. Trusting themselves, and others, is the bridge over the gap.

In trying to humanize the process of both teaching and learning, we discovered how easy it is to find oneself on the slippery slope of trusting others. How to give up control? How to gently illustrate the inequities of people being with people? How to keep ourselves open to new learning? The process of compiling this book took travel, time, energy, and lots of caffeine. It took, and yet, it gave. We were given this opportunity to listen to the stories people have been living. We interviewed many, many people. There were so many contributions that we could not use them all. We were overwhelmed with possible ways to make this book readable. Names have been changed so we can all relate to some of the some major issues as each person's stories and ideas unfold in the various chapters.

**Mirror reflections,** the first chapter of this book investigates the gap created by personal fears. By recognizing those fears, it becomes easier to go beyond them and begin the process of change. We can open up the floodgates of creativity and enjoy different ways of achieving life dreams.

In order to gain a personal glimpse into our own beliefs, the chapter, **Talking to** each other, invites us to look at the message behind the words we use. Also, have a little fun while searching for the words that "say" so much more than perhaps we realize.

We heard many accounts of the progress and hazards that people face as they involve others in their daily lives. As in the chapter, **Getting to know each other**, opportunities to involve others are all around us. Once we recognize choices are there, then we can begin to enjoy the beauty of sharing time together.

Growing in circles is a chapter that celebrates having people who can be counted on. It also illustrates some barriers that may be faced along the way. Assisting people to welcome more people in their lives may involve more help than family members alone can provide. These stories detail some of the daily experiences that might be encountered.

We examine partnerships in our towns and cities and investigate our roles in the chapter, **Working together.** As more people begin to make their needs known, more co-operation between established groups will be developed. The stories are positive and uplifting as they demonstrate successful strategies.

We must celebrate our changing roles. It doesn't matter whether we take a step cautiously onto the bridge of trust, or take a leap of faith and jump over the gap. Gaps will always present a challenge, but the bridge over those personal fears and external forces is there.

Chris, Barbara, Diane

# mirror reflections

There is a gap between wanting to go ahead and do something, and actually doing. Even when our responsibility is to proceed, our motivation is quite strong, and we are the only one who can make this incredible change...something gets lost. Fear stops us from carrying out what we know to be the best plan of action.

The gap between a strong vision and the implementing of necessary action can be disconcerting. The weightiness of inaction can plague us in all that we do. What is this fear of acting on what we believe to be true?

The people who shared the following stories, ideas and anecdotes told of looking at themselves first to find the answer. To hold up a mirror to reflect our own actions is to uncover the emotions within. We wish to help someone else as well as ourselves, but still we falter. We hesitate and begin to question ourselves. What if I overstep my bounds and ask too much of people? What if it doesn't work and I get blamed for setting expectations too high? Will I lose my job if I help people so much they won't need me anymore? In stopping to worry, we lose the momentum necessary to act. We stop ourselves from actualizing dreams with other people.

The "social" part of social services reminds us we are all subject to human emotion. We all have resilience to bounce back after exploring our feelings of self-doubt, and our resistance to change. To jump the gap is to make mistakes, to question ourselves and to move onward. Looking at our fears will help us to take the first steps of trusting that the bridge will carry us to the other side.

## Facing our fears

You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, 'I lived through this... I can take the next thing that comes along.... You must do the thing you think you cannot do.\*

I had some very anxious moments about supporting Pat. It was a window-washing job in a busy strip mall that backed onto the river and had a rocky decline. We couldn't easily take a few minutes away to talk if needed.

Pat tends to wander and has no safety awareness. I remember having nightmares over all the things that could possibly go wrong. Will he break windows? Will he get hit by a car? Would he fit in? Will I help him in the right way? And, how would all those windows get done?

I talked to Pat. I talked to co-workers. I talked to supervisors. I talked to friends. I talked to everybody! The answers I got from people were varied. One person suggested tying a rope to each of our waists (Too bad the windows were on the ground level!). Another was to have Pat sit in a lawn chair (Ever try washing windows from a lawn chair?). I received several more ridiculous and unusable solutions. The more anxious I became, the more my co-workers rubbed it in.

Well, to make a long story longer, Pat is a huge success, in spite of my fears. He is welcomed and assisted by other workers, so there are always people around. Pat wants to stay close to people who genuinely like him. He is more involved in his work because his co-workers expect it of him. There is no need for a lawn chair or a rope!

#### Facing our fears

Support workers are often afraid because they have chosen to support people as a career, yet in developing natural supports, the message is, "Anyone can do it. It's no big deal." Josie and Joe Citizen shouldn't be able to do it, because staff have had training! The fear is knowing that Josie and Joe Citizen can do it, and staff will have to let go of their control.



Last week at the mall, Sally said she wanted to be alone to shop. It made me very nervous and it was hard letting go, knowing she may have some difficulties. I waited and worried the whole time. Sure enough, Sally returned elated!

On the way home, Sally told me twice how much she enjoyed the time by herself. I could have sabotaged her time alone because of my own anxieties. I'm glad I didn't.



I can look back at this now and laugh, but I wonder how I ever made it through. I went shopping with Elaine. While in the department store, Elaine "borrowed" some candy. When confronted, Elaine went totally ballistic, and a huge tangle ensued. Elaine and I made our way across the store, and as luck would have it, we encountered one of the City's Finest en route. I was relieved that he was there to lend a hand, or so I thought. He asked what was going on, so I told him.

In the middle of my story, Elaine interrupted and said she had never met me before, and that I was trying to kidnap her. I stood there denying it, and the police officer got more and more confused. Finally, he had enough of our banter back and forth, and told us both to get into the cruiser. I asked him to call to verify that Elaine and I knew each other, and I noticed he put me in the back and Elaine got into the front seat of the car. He then explained to me the perils of abducting people. Well, he finally did call, and everything was cleared up. Elaine and I got a ride back downtown. On the way, I thought about this adventure. My worst fear was lived out, but we all survived!

We use all kinds of excuses for not introducing people to each other. "There are no part-time staff." "We have no time." "He really doesn't want to do that."

Martin goes, or doesn't go, to church depending on who works for him Sundays. Some say he doesn't want to go, but others insist he does. It isn't Martin changing his mind. I believe it is people afraid to face their own anxieties about helping Martin to meet other church members and be involved with the church.



My greatest accomplishment was when I was seen as a rebel, but all I was doing was fighting to ensure that a couple was heard. Thinking back, because it was so heated, I could have lost my job. It didn't matter, because the couple and their goal was much more important. A man and a woman had been dating for seven years and decided to get married. Everyone seemed to be in an uproar. I insisted that this couple should have more information about all that was involved, and that they could make a decision like any other couple in love.

This wasn't an easy battle. Neighbours, some family members, and even my coworkers wanted to avoid the issue of marriage as the natural progression of a relationship.

A lot of it is embarrassment. Too many support workers don't really feel comfortable with the people they are with it is a career, a job. Don't ask me to think of that person as being the same as me.

### FEAR NOT!

Many people shared experiences about how their adrenalin pumps and knees shake when tackling something new. Yikes! Draw from your experiences. Do you remember your first date, or when you helped someone find a job? Connect the two columns. Any answers could be right...that's what's really scary.

rears		Action				

Not feeling qualified enough	Practise phone call beforehand
I will be asked personal questions about the person I'm with	Make sure it is what the person wants
I don't know what to say, or how to say it	Find informal settings
The person I'm with won't be understood	Rehearse your successes in your mind
I'll sound stupid	Plan with the person who wants the involvement
I'm afraid I won't give enough support to the person I'm with	Recognize your own fears
I'm afraid I'll give too much support to the person I'm with	Just do it
The focus will be on me, rather than the person I'm with	Ask yourself, "What's the worst that can happen?"
I won't know the answers	Question whether or not you're needed in this situation
THE	Leave your professional hat off
I'll be intimidated	Remind yourself that we're all human
I'll end up defending a person, rather than facilitating	•
It will sound like charity	Remind yourself that you are not asking for favours
I will freeze, or stumble over my words	Find out what the person you are with wants you to do
I will make the person I'm with feel uncomfortable	Remember you are only a back-up for that person

#### The rule hook

We keep ourselves as busy as a hill of ants. But even the ants get to stop to go to a picnic sometime.

I could not figure out why Brian did not show up for our baseball game. He loves ball. It was a Saturday morning and our team was playing in a tournament. I called his home. I was told he could not go until he got his house-cleaning chores done. I could not believe it! I said, "So what! I'm coming to pick him up in ten minutes." It was a good thing Brian wasn't spending time in my home that day, because it was a mess. There was a tournament to play. What was more important?

It is interesting that those who spend time writing programs and goals for people are often the same people who cannot think of any goals to write for their own evaluations

One Saturday morning, Louise came down for breakfast. She was a little upset. She told me that she did not want to have to buy a fancy pink dress for an upcoming wedding. She wanted to buy a black skirt and top. I said, "Fine, it is your decision." Her mood changed instantly, and she became very excited. After returning from the store, she was proud of her decision and delighted to show off her new outfit. Her smile gave it all away!

I guess I didn't know all the rules. I was called in after that weekend and reprimanded by my supervisor. She told me that I had gone against Louise's sister's wishes.

Her sister had wanted Louise to buy a particular pink dress. The whole thing was blown out of proportion. I was told I was wrong. My heart told me I did the right thing. I know Louise felt good about deciding for herself.

#### The rule book

One morning I arrived at Lorraine and Ada's home. David, who had worked at their home during the night, was still hanging around, I guess to talk to me. Ada walked up to him to start a friendly conversation. Quickly, David turned to Ada and cut her off, saying, "Not now Ada. I'm off!" The message was loud and clear.



Bert is very handy and has many skills that involve working with his hands. He and I made up a list of all the places he might like to work, and then set out to apply to them. After about two months of checking out opportunities and investigating openings, Bert got a job at a small family run motel four blocks from his apartment. Great! It was small repair and custodial work, just what he had wanted. Well, it was great until Bert became dissatisfied with his job and started to go into his job late everyday.

Bert said he didn't like the job, so he quit. He searched out a different kind of job. The golf and country club hired Bert and gave him responsibility, a uniform and the job he had gone after. However, three months later, again Bert quit his job. In the following three years, there were ten jobs initiated and ten jobs terminated.

Although the agency that provides support puts "work" on his yearly goal plan, Bert and I feel it is not the avenue to focus on. Bert himself often asks for help in getting a job, and I help him. Other times, I assist him to work on any volunteer position that he is interested in.

There are so many things that Bert can do. We constantly comment on how skilled he is. He has grown in every position he has held. Last year, he was nominated for an award for his volunteer work and contributions at a non-profit agency. Now, and in the future, we will celebrate with Bert his work, paid or unpaid.

Support workers don't need to be creative and look for new ways of doing things when agencies fill every minute of their day. The agency has to trust and recognize that three cups left in the sink is okay if there's something else going on in town.

I got a call the other day from a woman who wanted to go through our agency's volunteer program so she could spend more time with her daughter during the day. We have formalized relationships so much that parents think they have to become "volunteers" to see their kids!



I was sitting at the deli counter waiting for someone who had gone to the store next door. The receptionist from the agency I work for saw me and asked if I was on a day off. I was embarrassed because I was supposed to be "supporting" someone, but I figure it was a compliment because I must have looked pretty natural!



I know situations where friends work around the staff's schedule. Kathy's friend, Sara, called and asked me when Kathy would be available to go out. It should be the other way around. My schedule should work around Sara and Kathy.

## you and I

I am a resident. Y o u reside.

I am admitted. You move in.

I am aggressive. You are assertive.

I have behaviour problems. You are rude.

I am non-compliant. You don't like being told what to do.

When I ask you out for dinner, it is an outing. When you ask someone out, it is a date.

- I don't know how many people have read the progress notes people write about me. I don't even know what is in there. You didn't speak to your best friend for a month after she read your journal.
- I made mistakes during my cheque-writing program. Someday I might get a bank account. You forgot to record some withdrawals from your account. The bank called to remind you.
- I wanted to talk with the nice-looking person behind us at the grocery store. I was told that it was inappropriate to talk to strangers. You first met your spouse in the produce department. You couldn't find the bean sprouts.
- I celebrated my birthday yesterday with five other residents and two staff members. I hope my family sends a card. Your family threw you a surprise party. Your brother couldn't make it from out of town. It sounded wonderful.
- My case manager sends a report every month to my guardian. It says everything I did wrong and some things I did right. You are still mad at your sister for calling your mom after you got that speeding ticket.
- I am on a special diet because I am five pounds over my ideal bodyweight. Your doctor gave up telling you.

I am learning household skills. You hate housework.

I am learning leisure skills. Your shirt says you are a "couch potato".

After I do my budget program tonight, I might get to go for a burger, if I have enough money. You were glad that the new French restaurant took your charge card.

My case manager, psychologist, R.N., occupational therapist, physical therapist, nutritionist and house staff set goals for me for the next year. You haven't decided what you want out of life.

Someday I will be discharged... maybe. You will move onward and upward.

from Elaine Popovich Lutheran Social Services, Midland

# Charting the Toliet waters

Note in a diary. I asked for more fun, and they wrote me a program.

Isobel had invited me over for tea one Sunday afternoon after church. When we entered her apartment, I noticed a little sign on the mirror of her hallway that said, "Please wipe your feet." I smiled a little at Isobel, and promptly did just that. We went into the kitchen, and she began to make the tea. Opening the cupboard doors to get out some mugs, I noticed more little notes about where dishes go, and to remember to turn the dishwasher on before leaving the house. I asked whether these little notes helped her and her roommate organize the kitchen. "Oh no," said Isobel. "We can't read. Those are the worker's notes."

The worst possible invasion of privacy is to publicly display a bowel movement chart on the bathroom wall.

I work the night shift in Dean and Barry's home. The biggest part of my duties is cleaning, while everyone is sleeping. It makes me question whether Dean and Barry, who have a "cleaning program" every Saturday morning, ever wonder where the dirt is.

Ted is usually a very neat and well-dressed man. But a few weeks ago, I noticed he wasn't changing his clothes everyday. His face appeared only half-shaved, and he was not his usual cheery self. One support worker wanted to help Ted by putting him on a program to remind him about personal care. "Hold on a minute!" said someone else.

"Ted has been out looking for a job for three months now, and hasn't had any luck. His support worker took a week off, because she felt drained from the rejection. Ted must feel the same way." That was a close one!



Pierre got up in the middle of the night and I gave him a cigarette, even though it went against his "smoking program". He'd had a rough day, and he said the smoke helped calm him so he could go to sleep.

The next day, I was accused of setting up the other staff. What would happen if Pierre gets up again and wants a smoke? What about consistency? Well, what about Pierre's "program" meeting his needs? I found out this "program" has been in place for three years, without any reassessment. We have to be adaptable and work with people. I feel the "program" and "data collection" sometimes come before the person's needs.

# As the rote changes

Our roles are changing. We need to support ourselves through the change, by turning to each other and working as a team.

The role of a support worker is to be there to fill in when there is no one else available. The worker should be the back-up person, the last resort, after turning to others in a person's life.

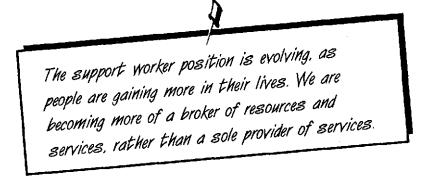
Harry had to stay in hospital for a few days. There weren't enough staff available to be with him, so his family was asked for help. Within three hours, friends, family, volunteers and one co-worker from Harry's part-time job made plans to be with Harry. We need to turn to other people as if it was an emergency. We tend to be more resourceful in crisis situations. It is terrific how people help if a need presents itself. All we have to do is ask.



We definitely over-support people. It is a hard concept to be there only when needed, because we tend to look at the "whole" activity. For example, if Sam needs a ride to the store to buy milk, we assume we should go in and help him buy it too. We're cutting off potential for contact with other people. We should give Sam only what he needs, not everything else associated with the activity.



Ed is a very independent man. He makes himself understood very well without using spoken language. He will often go down to a local bar where people know him. A co-worker of mine commented on how guilty he felt because we never spend enough time with Ed. I wondered, if Ed had more paid support, would he still be enjoying a cold one with his buddies?



Winnie used to go to the grocery store with a list of things to buy and would bother all the cashiers about where everything was. It got to the point that the grocery store employees would cringe when they saw her coming.

That is when I met Winnie. We went back to square one. We went into the store together. She learned where the food groups were located, to look at the label of the product, and finally, how to check the price. Within two weeks, Winnie had mastered the grocery store. She goes back to that same store where everyone knows her, and now they look forward to her coming in. Winnie enjoys being with other people and socializes at every opportunity. I simply helped Winnie organize her skills, so she could do what she needed to do. She is now treated with respect.



I think a big fear is that people will think you are not doing your job. We sabotage the natural development of friendships, because if people have friends, they won't need us. I had trouble trying to convince one support worker that it is all right to spend an hour alone while Andrea visits her friend. He shouldn't be there, but he feels guilty.



Keith is a man of ritual and routine. He must take his coat off and hang up his hat at every stop. Places without hat racks make him tense. But whose tension is it? I could call ahead to check if they have a hat rack. But it is his tension. Let him own it. I can help Keith realize, and live with the fact, that some places just don't have hat racks.

#### As the role changes

I was hired to help people meet more people. I didn't have any resources, so I turned to the community for everything. Delia needed a ride to the pool. I approached Delia's neighbour, and they went to the pool together. As I look back now, thank goodness I wasn't given any staffing resources. Delia and her neighbour gained a friendship which they still have today.

We are not doing anyone a favour by saying it's okay to "choose" anything you want. Choice involves a rejection of something. It means giving up, as well as receiving. We need to recognize both sides of choice.

The support worker looked at me funny when I checked inside my daughter's fridge at her apartment. I made her aware that if the food in the fridge is a month old, as a parent I'm going to get upset. My daughter does not understand mouldy jam that has been kept too long cannot be eaten. It makes me wonder about the level of care she is receiving, when "choice" is used as an excuse for not cleaning out the fridge.



People with developmental disabilities already have so many things to deal with because society is not always accepting. It doesn't help when people wear clothes that don't fit, or look awful. I know they may have chosen it from their closet that morning, but I'll tell a friend, or my husband, if their clothes don't match. I want Lance, my son, dressed well. He might have "chosen" lime green and orange, but I know he wants to look good.



A new worker came back into my office. She was puzzled over what her position was called, for the tax form. The employee manual had used the words: support worker, care giver, staff, case manager, prime worker and counsellor. She thought having so many names actually limited us in our role. She said she had heard people being told that a person couldn't help them because it was a different person's job.

# ON A ROLE

Find the words that are used to describe people who are paid to support other people.

a	С	0	r	d	d	s	W	i	r	С	3	r	2	d	2	j	е	s	b
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# talking to each other

Language is a medium to express our innermost emotions and needs. Sometimes, we are not aware of the message we send with the words we choose, or our tone of voice.

Recognizing that language has an impact, can be the first step toward change. We often talk of words that are "pet peeves". These words bother us to hear them, or if we, in fact, use them. Often, we develop a jargon or different set of words to describe the everyday actions or feelings of others. Yet, these words are often identified as the very same "pet peeves" which bother us when applied to our own actions.

Through stories and questions, we have used a lighter way to look at our beliefs and attitudes as they are reflected in our language. Investigating how we use words was important to the individuals who shared the following stories.

### **Pretend** Words

And torture one poor word ten thousand ways.\*

Carla got a job in a flower shop. About six weeks after she started, the employer asked me when she would be finished. I didn't understand. He said, "You said she was looking for a placement when you helped her in the interview. When does the placement end?" Carla was looking for a job, not a placement. The word "placement" had led the employer to believe it was a short-term position, not a real job.



A visitor came one day at dinner time. Someone asked, "Who is feeding Rusty today?" The visitor asked enthusiastically what kind of pet Rusty was. Oh boy, was I embarrassed. Rusty is a man who simply needs some help at mealtimes. Now we are careful to say, "Who is having dinner with Rusty today?"



Selina asked if we could go on an "outing". I asked what she would like to do. She said she needed food and wanted to go grocery shopping. Why is everything in her life an "outing"? Life boils down to a series of "outings" for people with disabilities. When is it time to just live?



Melissa is always thanking me for "taking her out" after an evening together. I keep telling her, "I didn't take you out. We went out together."

#### Pretend words

I can never understand why we refer to people as "going home" when they are going to visit their parents. It is as if a person is waiting at the apartment door and some day will be going home. I remember hearing one person say Henry was "going home" for Christmas to his brother's place. Henry had not seen his brother for a few years. In fact, Henry had never lived with his family. His home is where he lives today, his apartment. He was about to visit his family, which is wonderful. Let's celebrate the visit.



Every time a co-worker used the word "unit", I would feel my blood begin to boil. She would write in the log book, "George returned to the unit at 7:00 p.m." People always say I am too picky about the language we use, but I feel that if we say it, we must think it. Finally, one day, George said, "Stop using the word 'unit.' Promise me you will stop, and say my 'home' instead. I live here, in my apartment. I don't live in an institution anymore."



As soon as a person receives paid support, the address becomes the name of the person's home. It is no longer Craig's home, it is the "Front Street" home. How many people do you know who have their homes named, besides Elvis and Scarlett?



After a three month assessment, we were given 20 pages of things Carter couldn't and shouldn't ever do. We said, "Thank you very much," and promptly ignored it. We thought it would be better and much easier to ask Carter what he wanted to do. He stated, matter of factly, that he wanted a job working with people in a drug store. He didn't say he wanted to, "Increase his self-esteem," or "Be independent within three months," or "Increase opportunities for social interaction". The assessment had labelled him as a non-worker. Programs had labelled him as needy. Carter wanted a job. We helped him get it.

Words used to describe Angelo three years ago:

profound retardation
steals food
incontinent
very aggressive, resistive, non-compliant
sits on command
must have sedation and papoose board for appointments
has fixed, blank stare

Words used to describe Angelo today:

has a new friend
is a tenant in a new home with no plexi-glass
communicates with gestures
is a lot of fun to be with
less fearful when going out
uses his sense of humour

I am often asked whether this is the same person. He is the same guy. We see him differently, so we use different words.

If we have to use labels at all, we're not doing very well. When introducing people to each other, it is usually by name, relationship or common interests, not by hair colour or disability.

I think the word "consumer" is a poor descriptor for people who use support services because true consumers have choices about what they want. People do not have choice about what service they get. We're the only game in town.



I get upset when support workers say they are friends of people they support. If we are paid to be with someone, we are not their friend. One man told me, "If you are my friend, I don't want more friends because I don't need more people telling me what to do." Ever since then, I have recognized that I can have a friendly, caring relationship with someone I support, but it twists the meaning of friendship to say, I am their friend.

#### Pretend words

I wonder if paid people who say they are "friends" with people they support would be there if the pay cheque wasn't there. Friends give freely of themselves.

> Labels come and go. There's one word that will never become a dirty or unacceptable word: people. Makes sense.

It drives me crazy to hear those awfully patronizing endearments, like "Honey", "Dearie", etc. We do this to people who have a disability. One day I was in a restaurant when the waitress came up and called the person I was with "Sweetie". I started to get angry. But then she turned to me and, in asking for my order, called me "Sweetie" too! I realized that some people are just "Honey" and "Dearie" people. It's the people who don't use endearments for anyone else except people with disabilities that drive me crazy.



In describing an evening at the fitness centre, Carol wanted to avoid the use of the phrase, "well-behaved" when referring to Sam. Instead, she said that Sam had been "inconspicuous"!



After looking closely at the language we use, we decided, as a group, to be more aware. We each chose one word or phrase that we used that we felt lacked dignity. Whenever we were caught using it, we would throw 25 cents in a jar. When we had changed that word or phrase, we would move on to a new one. It was fun! When enough money had been accumulated, we went out together on a Friday night!

## What is gour message?

Recent studies, research and scientific data, show that six out of ten people report the hairs on the back of their neck stand up when confronted with particular words, phrases and actions. Explore your reactions to the following questions.

Own Your Own Stuff, and Stuff Your "Own-ning"

Are you referring to a popular 1960's song when you say, "My guys"?

Yes No

"I'd like to try him at..." is a phrase you use only when speaking of sending your dog, Rover, to obedience school.

Yes No

Do you say, "I have a person" and mean

I have a person-al opinion? Yes No
I have a person-ality? Yes No
I have a person's foot in my mouth? Yes No

Do we say "out" in the community because:

- we need a day-pass to life
- in-out is harder to say
- I don't know. In-zees and out-zees are for belly buttons

Who answers the phone?

- person who pays the bills
- person who makes the most money
- · person who is closest

#### What is your message?

The doorbell rings. You hear knocking. Nobody answers the door. Why not?

- · only staff answer the door
- no one else is home
- there is no Halloween candy left to give out anyway

The dental office calls to book an appointment. You...

- get out your day book and fill in the slot
- call Alice, it's her dentist
- put down the chocolate bar you were eating

You notice the hall closet door no longer closes. Pam says...

- it's her house, she'll clean it some rainy day soon
  - it's all staff's belongings, so they can clean it
  - let's call my mother. She'll know a garage sale or second hand store to give it to.

How many people does it take to help Adele get a job?

- 12 to sit around a table and plan it. One to drop her off.
- one person at Manpower
- she'd rather have a perm

Measure your reaction to the following stories:

1 =one hair on your neck is raised. 5 =all hairs on your neck are raised.

I was being interviewed for a position at a group home. The supervisor told me I would be with Gordie, Susie and Margie. I said I didn't realize the job was supporting children. She replied, "Oh no, they are seniors."

1 2 3 4 5

I heard someone say the other day, "It's time to get the wheelchairs ready for their ride." I immediately pictured the mobility bus full of empty wheelchairs taking a cruise around town.

1 2 3 4 5

So, how did your hairs measure UP?

# Hearing aids

I really like people who accept my way of telling them how to do things. You get to know the kind of people who are ready to listen to you. I mean truly listen, not just pretend.

One of the greatest fears I have is not being allowed to tell people what I feel deep down inside.



When I worked at Becky's place on Saturdays, she and I developed a special time together. In the afternoon when her roommates had gone out to shop or for lunch, she would take a blanket and curl up on the couch. Then she would ask me to sit down and talk. Often she would talk about her life in the past, and of living on a farm with her parents. Sometimes we talked about church. Lots of times we just sat together, drinking mugs of soup.

I moved, but came back to visit and to attend her planning meeting for the upcoming year. Surrounded by staff at the meeting, Becky blurted out, "You must come back. I don't have anyone to talk to."



I want to control my own life. The staff complain about spending so much time on the phone making appointments, setting up conferences and talking to family about visits. Well, whose appointments, conferences and family are we talking about? If it is mine, let me talk. I might need special phone equipment, but my friend has a speaker phone that is programmed. I'd like to see if it would work for me. When others get to talk, sometimes they get confused and think they get to decide too. Voice does not mean power. I want my life so I can be busy and tired at the end of the day, like the staff are.

#### Hearing aids

People should repeat back to me what I said to make sure that they've got it right. It might take more time, but let's be honest - you want to get it right, don't you?

## D

If you're with someone and there's some weird behaviour, don't pass it off as if nothing has happened. It gives others permission to ignore the person. We should see this as an opportunity to help people communicate directly with each other.

# 2

I didn't feel comfortable when I first met Sharon because she doesn't use language easily. To help other people feel comfortable, they need to know I had that experience too. Then I can help them to learn how Sharon communicates.



Leroy isn't allowed to get angry. We don't listen when he does. I read a log book entry the other night: "Leroy told me to stop treating him like a damn child."

I wanted to cheer Leroy! Staff didn't get it though. They were recording his bad language, but didn't really hear his message. They were treating him like a child and didn't see their own actions. Instead of treating this like a "level two behaviour", we need to see Leroy is angry. He may do things in a passionate, uncontrolled way but that is human emotion.



We have good ideas about helping people find jobs, but I always ask, "What does the person think? Your say is not the bottom line." Now they won't approach me until they have heard what the person thinks. They know I'm not interested in hearing any ideas they haven't talked out with the person first.

One of the most frustrating things is not understanding what people are saying to you. It takes time to listen and it is much harder than it seems.

I know I have often waited half an hour for my son to finish his sentence. He may get stuck on one sound, or perhaps it is the concept that is hard to put into words. I have noticed when I visit his home that some people feel more comfortable than others talking to Alfred. Alfred needs more than a question directed at him, like, "Do you want shepherd's pie or pasta?" Inviting him to come into the kitchen, and help find something for dinner is a more inviting way to begin a conversation about food. Talking naturally helps us to feel more at ease. It also makes Alfred feel more like he has a choice in these little decisions.



I had told Pearl I would be able to talk to her "in a minute". Three hours later, Pearl was still waiting. She had turned down a lunch invitation because I was going to talk to her "in a minute".



Bill is deaf and needed some neurological testing. The first set of tests was completed, and another appointment was made for more tests within two weeks. When Bill went back, much to his surprise and delight, the X-ray technicians had learned some signs. They wanted to reassure Bill that he was doing well. What a wonderful change from two years ago, when other technicians yelled at him and gave instructions when his back was turned. Attitude sure makes a difference.

## getting to know) each other

Getting to know each other is easier than we think. We need to interact with one another. Yet, we fill our minds with "what if's". What if the person doesn't like me? What if I stumble over my words? What if my mind goes blank while I'm introducing two people to each other? What if I fail to do my job? What if I make someone feel uncomfortable? What if I need special training to talk to an individual? What if I'm not smart enough to know what to do?

The "what if's" build a gap. They stop us from remembering we are all human, and stop us from getting what we want out of life. They stop us from being ourselves. In response, we build artificial worlds to protect us from failing in the real world. We build programs and systems and create roles for ourselves and others. These have nothing to do with being neighbours, co-workers, friends, family and fellow citizens.

It is time to open our eyes and return to the real world, where people getting to know each other is very natural. The gap blinds us to what is already going on all around us. We can be our own worst enemies. So often, we are the barrier to people getting to know each other because of our own fears. The following chapter tells of struggles to jump the gap of personal fears.

## Opening our eges

Taking a leap of faith involves trusting ourselves and others in our community. "Our role includes introducing people, nurturing existing relationships, and following up on people who 'click'"\*.

We have to watch for open doors. We have to jump at chances to introduce people to each other. Sometimes, we just have to ask.

Isaac kept going over to another table in the restaurant where a woman was sitting alone. She responded warmly. Blaine tried to encourage Isaac to come back to their table, but he was pretty insistent. Finally, Blaine approached the woman and asked if Isaac could join her for dinner. She said, "Yes." Blaine was pleased the two were getting to know each other. He went back and had dinner alone!

25

I really like being with Manny. Other people should have opportunities to get to know him as I have. It's not asking for a favour. Other people will get as much from his friendship as I do.

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I think people often use confidentiality as an excuse for not introducing people to each other.

#### Opening our eyes

Having a volunteer services department can discourage us from helping people meet new people, because we rely on the volunteer coordinator to "get the person a volunteer". As if that replaces meeting people daily. It's our job to help people meet new people.



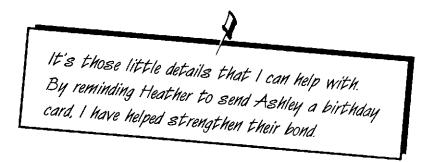
I like to meet my neighbours, so I'll feel comfortable if I have to ask for something, like borrowing a cup of sugar. But, when I'm visiting my sister in her home, it's easier for me to run to the store if there's no sugar or other supplies in the house, than to help her to meet the neighbours. I realize it should be as important for my sister to meet her neighbours, as it is for me to meet mine.



It was easy to introduce Jay and John when we all met for the first time at the neighbourhood garage sale. It's a very different story though when Jay and I walked into the Lions Club meeting. I didn't know whether to search out the president, or the membership coordinator, or scan the room for a face I knew. All I knew was there was protocol to follow at this meeting. I was nervous about making introductions. There are different ways to make introductions, and every situation changes.



There's a difference between attending something and participating in it. Jill loves coins. She could have joined the coin club. She would not have enjoyed it though, because of the complicated meetings. It would have looked great on Jill's "file" to say she was a member of the local coin club. But, even though she could have attended meetings, it wouldn't have had meaning for her. Instead, we approached the coin club and found someone who was interested in sharing interests in coins with Jill.



Larry's Mom calls often. His mom would talk to me, then ask for the information to be passed on to Larry. I started to prepare myself when I knew she was going to call. Before she could get into a big conversation with me, I would gently say, "Just a minute, I'll get Larry for you. I can talk to you after that if you want." It took some time for her to feel comfortable, but today it is working, and Larry and his mom have great conversations.

## 2

Lynne, a friend of April's, came to me to ask if she could bring another friend when she goes out with April. Having to ask if more friends can come! There must have been an unconscious message about having to "clear" everything, including friendship, with me.

We tend to look for the "perfect" friend for people.

"If they are really friends, they will see the
person XXX number of times a month." It's so
unnatural because if we look at our own lives.
how often do we see our friends? We judge other
people's friendships by noticing or recording how
often we can say they went out.

I was wondering why Janice, a friend of Sandra's, had not been to visit recently. When I called to touch base, Janice told me she had stopped coming by Sandra's house. The staff there had been phoning her and telling her when it would be convenient for her to go out with Sandra. Janice felt that demands had been placed on her friendship. Janice was going to Sandra's work during lunch hours to spend time with her, rather than confront the staff about her feelings.

#### Opening our eyes

Kealy's mother had died early in November. She didn't know until a month later when her sister, Joan, called to say there were Christmas gifts for her. Joan, who barely knew Kealy, called to see if this was the right address to send on the gifts. The story could have ended right there, because many of us are loath to interfere in a family's grieving. But someone said, "What about Kealy? She has suffered a loss too. Can't we try to help the family meet Kealy again?"

The reuniting started in small ways. Kealy was encouraged to send a note thanking Joan for mailing the gifts. A photo and letter followed a month later. A phone call to check some family history was initiated by support workers, but ended with Kealy saying her first words to her sister in 30 years. Joan confessed to being under the impression that Kealy couldn't talk, think or move on her own.

Soon after, Kealy was invited to meet Joan's family. The small trips with her sister have made a real difference to Kealy. Plans are being made to spend a few days together in the summer. Joan has said that she has gained a sister since being reunited with Kealy. Starting in small ways can make a big difference when nurturing a relationship.

Sometimes we need to open our eyes to what is already happening, and when it needs a nudge to help it along!

Sue had been taking a cab to work for years, and usually it was the same cabdriver every morning. Everyone knew they got along great. They would joke and tease each other. This had been going on for quite a while when it occurred to us that they had established a relationship. All it took to develop that was to say to Sue and the cabdriver, "You two get along so great, ever thought about getting together for coffee?" That's all it took. The cabdriver and Sue jumped at the chance and now get together regularly.

I was with Alisha having a drink. We struck up a conversation with a woman at the next table. I got up to get another drink, and Alisha and the woman kept chatting. I thought, "This is great!" I reached for my purse to pull out my business card to tell her about our volunteer program. I caught myself and thought, "It's already happening." I returned, and sat back while the two women continued to talk. When it was time to go, I casually mentioned that we come here every week at this time and it would be great to see her again next week. My business card had almost interfered with something very natural.

Imagine what this woman might have thought had she got a card!

"Oh no, she's going to try and sell me insurance."

"Oh dear, I don't have time to volunteer."

"I guess I shouldn't be talking to Alisha because I haven't been trained."



Yesterday, Nina and I were walking through the mall. A manager of one of the stores stopped to talk to Nina. They carried on a conversation. After their visit, Nina and I went on. I asked Nina who that was. She told me she and her mom shopped at the store where this lady had once worked. I asked Nina if she was interested in getting to know her better and she said, "Yes." She and I went back to the store. I said to the manager, "It appeared to me that you and Nina are quite comfortable with each other." She said, "It was good to see Nina again." I suggested the two get together for lunch. The manager said that sounded like a good idea, and she and Nina made plans to get together the next week!



## To know, know, know you

Trust people and trust your own judgement. To trust, we must get to know a person in all types of environments.

The first few weeks, Diane and I spent time getting to know one another. It was hard finding places in the hospital to do that. We would go out of the hospital and that helped because my senses came alive. I started to have a different feeling about things.\*

When I first walked into the hospital room to meet Brenda, I was overwhelmed by the environment. From a distance, I could hear people moaning, buzzers ringing and someone yelling, "Nurse, nurse!" I knew I could not possibly get to know Brenda and help her get what she wanted in this place. So we left. It would have been easier to stay at the hospital, but I would not have been able to get to know her interests if we had stayed in the common room with all the people and noise.



Most days, Ella would arrive and greet everyone with a cheerful smile. Then, for about a week, she was withdrawn, quiet and wouldn't talk to anyone in the building, despite repeated efforts. Finally, it was suggested she go out with someone to talk.

For whatever reasons, Ella wasn't able to open up while at the office. She needed to feel comfortable in discussing very personal topics and that meant finding a more personal environment.

It was an eye-opener of a meeting. Phil's annual service review brought together several people who knew Phil well. Or so we thought. It turns out we all knew Phil only in pieces and parts. One person knew he could make change. Others insisted he couldn't. Someone talked of Phil's dream job, while several people said they had no idea Phil knew what kind of job he wanted. The only person who had the whole picture was a friend of Phil's. We had all come from our "specialized" areas: vocational, residential, day program, literacy program. Phil's friend had spent time with him outside any particular program. He was the only one who had truly gotten to know Phil.



As a manager, I made it clear that new staff were not allowed to read files for the first two weeks. They were expected to get to know people by being with them, not by reading about them.



So often, we end up getting people jobs that they can't, or don't want to do, because it's an "employment opportunity". Frank got a job at a small store downtown. His duties included washing windows and wiping the mirrors in the change rooms. Yet, Frank had absolutely no interest in this. Lloyd would end up doing the work while Frank socialized with the store owner. When it was time to go, Lloyd would grimace while Frank was handed his pay. Finally, the store owner said, "Let's call a spade a spade. Frank hates the work, but we both like visiting." From then on, Frank would pick up coffee and arrive for coffee time. The two have a great relationship and Lloyd provides only transportation.



We had a meeting and asked, "If you were new in town, how would you meet new people?" Most said they didn't know because they already had their own circle of friends. I thought this was kind of strange. We talk all the time about helping people meet other people, but how can we do this when we don't do it for ourselves?

## Pounding the patfement

Instead of getting jobs for people, we help people get their own jobs.

We no longer go out and get jobs, and then try and slot people into them. We work with people to help them get the job they want. We do pursue employment opportunities, but they are posted for everyone to have a look at.

If we get jobs for people, why should they take responsibility for losing them? We set people up to believe success or failure at jobs is a staff responsibility.

I feel too uncomfortable phoning potential employers and telling them about a person, without that person being there. It's like talking behind someone's back. If I have to make an initial call, I always ask the person first what they would like me to say, and how they would like me to explain my role. And I make sure the person is with me beside the phone.



Not all people are great employment support workers, or best in an aquafit class. Everyone puts goals up on a board and we say, "Who is interested in helping Clarissa join the painting class?" Then we double-check with Clarissa.

#### Pounding the pavement

We used to do five cold calls a week to see if we could find out about meeting employers and setting up interviews. We have changed, so that we now set up tours of the business, or job information meetings. A person might be in that job for years to come, so we try to be a little more thoughtful, and less rushed.



We asked people we support for help in doing some role playing. Gene took on the role of the support worker, and we asked him how he would approach an employer. When the acting employer asked Gene to explain what he was doing there, he said, "I'm here to get her (pointing at acting employee) a job." Boy, did that tell us what kind of message we are sending. If people we support think it's our role to get jobs, rather than help people get their own jobs, no wonder employers and employees think we have all the answers.

Begging. Pity. Working for free in a previously paid position. These are not helping people find jobs. These are counter-productive attitudes and actions.

Eric was at a factory for about six months when I talked with him about getting paid for his work. I helped Eric approach the employer to ask for wages. The employer's response was that he had never had to pay people with disabilities before and he wasn't going to start now. Eric decided to stay in the job. Eventually, Eric decided he did want money for his labour and found a paying job. We're trying to undo now what we did five years ago, when we had the attitude that, "Anything is better than nothing." It's not good enough anymore.

## How to be invisible and other great tricks

I think it's important to be invisible. I don't think we realize we're even being a barrier sometimes. We answer for people. We walk ahead of them. Then we get angry when other people talk to us and not the person we're with. We are the role models for other members of the public.

I remember I was at a birthday party with lots of people. A woman who uses a wheelchair pulled herself up to the end of the table, and began chatting. She asked the lady beside her for help cutting up her food. Another woman, who was obviously her support worker, saw this and practically ran across the room to get to her and cut up the food, even though the woman beside her had already started to help. I was embarrassed just watching.



What kind of message are we giving by the way we stand when we are with people? At work, our supervisor asked if she could videotape us to review the way we support people. Everyone agreed, reluctantly. To see myself all hunched over the person seated in a wheelchair gave me the willies. Other people sat down so that we were all at eye level, and that made it easier to talk. I barely let go of Seth during that first hour of taping, as I was constantly touching his chair or in his space. It was disturbing that I almost seemed like his jailer. When the tape was reviewed, we heard someone joking when lifting Seth, that he had been putting on a few pounds. What we sometimes say to make conversation can really sound insensitive.



Lucille always called me to arrange her hair appointments. I did initially make the arrangements, but then I realized Lucille could do this for herself. As long as I did it for her, she would keep asking me. I had to let go so Lucille could do things for herself.

Bob had a support worker go with him to his job. At lunchtime, they were leaving the job site and going to the support worker's house for lunch. How's he going to meet co-workers this way? What kind of image does that project? He didn't meet people, and never became part of the workplace. It was a seasonal job, but I bet he won't get it again this summer, and I don't think it's because of his work skills.



As Joe's interview started, I began telling the employer all about who I was, and about the agency programs. In the meantime, Joe wandered away. The employer asked me, "Tell me again, what organization do you work for?" I realized that Joe, who was there applying for a position, had nothing to do with the interview. I've learned that I'm not there to talk about where I work, but to support the job applicant.

The beauty of helping people is that you don't have to know it all. You don't have to be the "boss". All you have to concentrate on is listening to what the person wants and following the lead.

We were looking at improving the ways we support people to find community involvements. We videotaped role playing. One of the things that became obvious was that we were always standing in front of the person who wanted to become involved, or way off to the side. This created a triangle, and no one knew who to look at. We decided to always ask ourselves: Who is facing heart-to-heart in the interaction? Well, this is a great way to make sure we aren't interfering physically with the two people in conversation.

One day, I was videotaping another role play. Rob and Jan were practising approaching an employer. Jan kept trying to stand a little behind Rob, so that Rob and the employer would be facing each other. Rob wasn't used to having centre stage, so would keep trying to get behind Jan. Pretty soon, they were out of view of the camera lens because they both kept trying to stand behind each other!

#### How to be invisible and other great tricks

I catch myself walking ahead of Carol on our way to the grocery store. At times, I have answered for her without meaning to. I want to stop people from turning to me when looking for Carol's answer, but I know I have unconsciously taught them to do this. I bite my tongue a lot now, for good reason, and turn and look at Carol to see her response.



Helen and I were at dinner the other night. The waiter asked me what Helen would like to order. I said I didn't know, and turned to Helen. Helen pointed to the item on the menu she wanted. When the waiter asked me for confirmation, I said, "I believe her!" When it came time for dessert, the waiter turned to Helen and asked her to point to what she wanted on the dessert menu.



Terry and I went to a shoe store. The person working behind the counter knew Terry. She called him by name and they had a little conversation. Then she turned to me and asked what kind of shoes Terry wanted. I stood there dumbfounded. She was looking right at me. Silence is golden. Then I smiled and said, "I really have no idea." She then turned to Terry and asked him. When we returned a few months later to buy winter boots, she talked to Terry and avoided me completely!

## Trusting the bridge is there

People respond to the expectations we set. When we turn to others, we can trust that the bridge over hesitancies can be built together.

All her life, Anna had been told that she would never have straight teeth unless they were all pulled out, and she got dentures. Specialists in orthodontia were consulted, but they all had the same answer. Anna's own dentist, Dr. Peter, saw how very much Anna's personality was affected by her crooked teeth. He went out on his own, took a course, and learned the procedure of straightening teeth himself. Dr. Peter is very proud of his efforts for Anna. He talked to Anna about every stage of the procedure. It is wonderful. He is so excited that he helped Anna get what she wanted. He tells her how beautiful her smile is, and she tells him how happy she feels. If only we all looked forward to going to the dentist that much!



Mike was interested in a volunteer position. When he arrived for his interview, he stopped in the parking lot and sat down. He wouldn't get up and go in. Lori went in and told the volunteer coordinator that Mike wouldn't come in. The volunteer coordinator said Mike must be anxious, and she would go to him. They did the interview in the parking lot. Then Mike got up, went in and had a tour. Two years later, he's still doing volunteer work there. You have to be honest and be willing to ask.



Society is generally much more tolerant than we allow. I remember when Robin started to become anxious at the end of a hockey game. Sitting in a car calms her, but her driver hadn't arrived yet. Jane approached a family and asked if Robin and she could sit in their car for a bit. The family all piled back in with Robin and Jane, cranked the radio and sat there for 10 minutes. They all got out when Robin was calm. They said their goodbyes and no one saw each other ever again! The family didn't see it as a big deal because Jane didn't make a huge scene out of it.

### Trusting the bridge is there

I was with Gina at a department store when she decided to explore, in high speed, the check-out and the cashier's area. My first instinct was, of course, to go running after her. That would have looked very silly. I found the floor manager, and told him that Gina was obviously very curious about their work area. When he asked me to deal with it, I replied honestly that it wasn't likely Gina would listen to me, but if he and the cashiers let her know she was disrupting business, it might help Gina understand. They did speak directly to Gina. It wasn't a magical ending or anything, but Gina did relax. We finished our shopping and left. I fought the urge to apologize for Gina, and I didn't. It was not my place to speak for Gina.



Luke was apartment hunting. When he found one he liked, we met with the landlord. Luke doesn't use language to communicate, so I did most of the talking. The landlord seemed reluctant, but didn't ask any questions. I got the feeling Luke wouldn't get the apartment. There were other people waiting outside the door to see the place. I finally said, "You seem hesitant. Do you have any questions about my role?" Well, he opened right up and asked a pile of questions about rent getting paid, about safety issues. Once I acknowledged he might have questions, it was as if I gave him permission to ask. Luke got the apartment.



One of the local grocery stores serves free coffee to their customers. Jim loves coffee. The store manager called me to complain that Jim was continually helping himself to the coffee, and would I please have a talk with him. I agreed that Jim was probably abusing the coffee privileges, but it would be much better if he asked Jim to stop. I basically gave him the confidence to treat him like anybody else who was drinking the pot dry! I followed up later. The manager told me that he appreciated my call, and said that it wasn't that hard to tell Jim after all. Maybe next time, I won't get a call because the manager will feel comfortable dealing with a concern himself.

We have been seen as the fix-it specialists. We are getting better at not always trying to fix things. We want to help others feel comfortable in responding.

I got a call from the transit manager. He said Maurice hadn't bought his bus pass yet and it was almost mid-month. I asked him what he would do to other customers who didn't have a bus pass. "Wouldn't let them on!", he responded. I suggested the bus drivers need to tell Maurice he wouldn't be allowed on the bus without a pass. And yes, the drivers should follow through if necessary. I heard a sigh of relief. The transit manager was not thrilled at having to chase down third parties, but felt an obligation. I hope I helped him realize his obligation was to treat Maurice like any other bus rider.



Rita and I often walked down to a local bakery. This was a popular stop, and there was usually a lineup. Rita found this annoying and would get anxious. While in line, she would rock back and forth. The women behind the counter could see that Rita did not like waiting. After learning her name, they reassured her that they would serve her soon. Over time, it was clear to me that the three women had clicked, and perhaps I was a barrier by my presence.

Now, Rita goes to the bakery by herself. She stands in line and waits, knowing that she will get to visit.

At Christmas, I sent them a note telling them what a great friendship Rita had gained in the past few months. The women told me that they cried when they got the note. They had not realized what a difference they had made. Since then, the two women and Rita have strengthened their relationship even more. I am glad I sent that note. People need to know even the small stuff is important.

# growing in circles

P eople told us that although building a circle of friends sounded like a good idea, they had experienced many fears concerning their own involvement. Who do I call to get a circle started? Will it work? What happens if people don't want to take part? What happens if members can't agree? Would the members stay involved?

In our journey, we realized that there are no secret formulas, or written plans that can give all the answers. People told us of creative, and less traditional approaches. Reaching out to welcome family, friends, coworkers, neighbours, church members, classmates, team members and more, means trusting all will be part of the struggles and celebrations. Upon inclusion, people have felt renewed, energized and more at peace with themselves. Gaining, as well as giving, is a reminder that we are all in this together.

## Who ya gonna call?

A friend of Jeff's started talking to us about a circle of friends. She told us about other people and places where it was working. She showed us we didn't have to follow the crowd and go the conventional route - that there are other options most parents aren't aware of. We didn't know a whole lot about circles, but we went ahead. Bob and Jeff and I met with her and started a list of people who might be interested in developing a friendship with Jeff. It included everyone from old teachers and neighbours to former staff who used to work with Jeff. She did all the calling because I was uncomfortable with phoning and asking people if they were interested in being involved in Jeff's life. I think parents from my era don't like to ask for help. Maybe younger parents don't feel that way.\*

As Jeff's friend, I wanted to make those calls, but I can honestly say that I was nervous. What would I say? How would I break the ice? What do I say if people say, "No"? How would I respond to people's questions? I started to prepare myself by making some mental notes. I wanted to be sincere, and not sound rehearsed. Before I picked up the phone, I reminded myself of what I was offering people. This wasn't just for Jeff, it was also a chance for friendship for them too. One of the people I called was Jeff's physiotherapist. I said to him, "I am a friend of Jeff's and I'm helping Jeff and his parents plan for his future. Jean, Jeff's mother, told me that she noticed how much Jeff enjoys spending time with you. We're inviting people Jeff likes to be part of the planning and wondered if you would be interested."

After the first few minutes, the conversation became quite natural! I made many calls. Some people were interested and others were not. One important thing I stressed was that people shouldn't feel they had to get involved. Not pressuring people was important to Jeff's parents.

<sup>\*</sup> Excerpt from The brains, heart and soul, Her shoes are brown and other stories, 1993

### Who ya gonna call?

It was Ken's annual goal-planning meeting. I was there because I am Ken's support worker during the day. This was the first time Ken had invited me. As I waited for the meeting to start, I kept on expecting more people to come. But, no one did. As we sat around in Ken's living room, the only people there were staff. During the meeting, Ken commented how he would like more friends in his life. We had no idea where to begin or who to call. Judith, who works for Ken in his home, thought perhaps she could call ex-staff who had worked with Ken in the past. That was the beginning. I think Judith made so many calls that she got callouses on her fingers from dialling the phone! It paid off. For the first time in Ken's life, he has people who come together because they like him and Ken likes them. Even though you may think there's nowhere to start, there is a place to start. Trust!

### Dear diary

#### Feb. 24

Dear Diary, I am nervous about helping out at Cindy's circle of friends without being "super leader". I want everyone to feel comfortable and share their thoughts, which means I need to know when to keep my mouth shut! All calls have been made and I think there will be at least 10 people there.

#### April 16

Dear Diary, Things are going great! Still lots of people coming. We're talking a lot with Cindy about her dreams for the future. I feel uncomfortable when Cindy's parents turn to me for approval on decisions. They know their daughter better than I do, but how do I help them realize I don't have all the answers?

#### May 19

Dear Diary, I am not sure how to help Bonnie realize that she often pushes her views onto Cindy. I know she means well. Tonight, when Bonnie started to take over, I tried to re-direct questions and comments to Cindy. This seemed to slow Bonnie down. I will continue to help Bonnie see Cindy as a decision-maker. For the next gathering, I think I will talk generally about the importance of listening to Cindy carefully, so Bonnie will not feel singled out.

#### June 14

Dear Diary, Cindy's circle has been growing strong. I know I have to become less of the leader, and try to take a back seat role. At the last get-together, I went into the kitchen, made the coffee, and got the snacks ready while the group was still talking. This was a chance for everyone to get to know each other without me "running the meeting".

#### *July 12*

Dear Diary, It's so neat to see everyone in Cindy's circle has a part to play! Cindy's minister rarely misses a circle get-together. Although he and Cindy would like to see each other more, he finds it hard because of his busy schedule. I think that his greatest gift is remembering to invite Cindy to all the church social functions. Over the years, he has introduced Cindy to many people.

#### Aug. 10

Dear Diary, A few of Cindy's friends are setting up a surprise birthday party for her. We've been concentrating on planning so much. Instead of a September gettogether, it's time to get-together and party!

## **Growing** many wags

Circles can do different things. I'm not involved just for the person who needs me. I need him too.

A circle of friends is not just being part of the person's social life, it means being part of the person's whole life. It can mean helping out at a spring cleaning party because the windows haven't been washed, and you want a clean home for your son or daughter.

To safeguard means there is a commitment to get back together if a need arises. That is what's great about circles. People can be called together for a specific reason, at any time.

Randy's circle had been meeting occasionally for three years. The group includes Randy, his brother, Ted, Leo, a co-worker, Wanda, a past teacher and his cousin, Louis. I am the only paid person. We did not meet as often after he had moved into his new apartment, because things were going smoothly. Then, Randy was laid off. He had been working full-time and was totally devastated by this change in his life. I quickly called his circle together. We started meeting more frequently because Randy needed people who cared to help him through tough times.



Our family had gone through a complete hassle with support services for our son, Donald. Different workers came and left our home constantly. With the help of Jessica, from the local Association for Community Living, a circle of friends was formed for Donald. Now, once a week, he goes to the home of a family friend after school. He plays with kids his own age, has supper and then my husband picks him up. Finally, we have respite! Knowing Donald is having a great time, and our friends are enjoying his company, gives us the peace of mind so that we can enjoy our time alone. Sometimes, we even have a romantic dinner!

I think there should be information for siblings who have a brother or a sister with a disability. I won't necessarily talk to my parents about my feelings. I don't, because I realize they have enough on their plate. I'd like to see support groups for siblings.



Brian's brother, Pete, tells how he and his sister felt differently from their parents.

We had a big meeting where the local association and our family got together. We all got to ask questions and talk about our fears. Again, Linda and I had to steer Mom in the right direction. I knew Brian was capable of so much more. I treated him like the rest of my brothers and expected the same from him. Fear - yes, but I never had any doubt\*



Marilyn's circle became the vehicle that ultimately changed her life. Marilyn chose these people as her listeners, supporters and believers. Marilyn's circle has grown in different ways. Some people, who first became involved, are not as involved today. But that's okay! As Marilyn says, "I have more people in my life. My formal circle has helped me gain a host of informal circles. I like having friends drop in. I like the ladies I sketch with on Tuesdays, and going to socials at my church. That's what's so great about circles!"

<sup>\*</sup>Excerpt from Always my brother, Her shoes are brown and other stories, 1993

## Working together

Working together to build partnerships can benefit us all. People told us that cooperation among services, businesses, and groups is critical if we want to belong within our community. We stop this flow of involvement with feelings of hesitation and doubt. Will it take too much of our resources (time, energy, money) to support individuals in more ways? What if other organizations don't respect our philosophy? What do I have to give up? This is so new. Do I understand all the implications?

Beginning partnerships with established members of our cities and towns can be a new challenge. In the past, all entities were separate. A change may bring political and public attention. Recreation, education, social services, religious affiliations and business can work together today to realize shared visions. To struggle and grow in this area has been highlighted in the following stories.

## Jumping With others

The word "partnership" may be an overused word, but community partnerships are important. We can't do it alone anymore.

It was a difficult situation. Two people new to town needed support, but no single agency was able to do it alone. Although the philosophy of the three agencies differed, we were committed to working together. One agency was able to hire the staff. Our agency offered to supervise the staff. A third agency provided advocacy and counselling services. Together, we found a way.

The onus is on each of us to help others
understand our vision. But we do not present it
as the only one. We cannot be evangelists. We
do not have all the answers. If people understand
our vision, we don't have to preach.

Our town is looking at "supportive housing". We know that many people who access our services are aging. It is our hope that, as a community, we can develop a housing plan that will include all aging people who may need some support. As an agency, we do not want to develop a separate system only for people who access our services. We are all part of the same community!



The two biggest barriers to working with other agencies are suspicion and ownership. There is a feeling that "their" philosophies are different so "they" must be wrong. They are "our" clients and we don't want others to do something bad to them.

#### Jumping with others

Our agency wants to be known as an enabler. We turn to members of our community to become involved. But, we have to do the same for other local services like the police department, the hospital and local businesses. We can't keep saying, "It's their job to provide that service," without helping them. That would be dumping.



We don't always have to keep running back to the Ministry to ask for more money. We have to take a good look at our resources and come up with creative solutions. We should be more like a business. We need to look at it as a creative enterprise shared by everyone.



I am involved in several committees in my community that have nothing to do with supporting people with disabilities. I feel it is a vital part of community living. While what I learn from being part of these groups is valuable, I am also a resource to other committee members. However, sometimes my time spent with these "outside" committees is questioned. As far as I'm concerned, this is the last place to cut my time, because it doesn't serve our purpose to live in a vacuum.

## Genuine partnership

Excerpts from conversations with John Lord, Coordinator, Centre for Research and Education in Human Services, Kitchener, Ontario.

There's been a lot of rhetoric about partnership, and confusion about the difference between partnership and consultation. Consultation means we ask people what they think about things professionals have drawn up. Genuine partnership moves way beyond consultation. It means involving people from the start, who have a stake in the outcome, as opposed to waiting until the policies and guidelines have already been drawn up. Families and people with disabilities have often been left in the lurch around things like case conferences, and many of the other "so-called" partnerships.

I think we've learned over the last few years that genuine partnership is really quite difficult to carry out, but has more meaningful outcomes for everybody in the long run.

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We need to redefine what we mean by genuine partnership. We need to rethink who we want involved in that process. Historically, we've always connected agency to agency, thinking that was the best way to provide support to people with disabilities. We now know that if we want to support people's wishes to be in community life, we need to think through who else might be partners in that process. That leads to new kinds of exciting partnerships with neighbours, with church groups, with city hall, with all kinds of natural networks that people have in the community, which up to now, have very seldom been tapped.

We've also learned that effective partnerships are enhanced when professionals can leave their professional hats at the door. It allows for going beyond their specific training in a particular body of knowledge, and really getting into listening and sharing. Genuine partnerships also recognize that power differences do exist, but that each person's experience and expertise make a contribution.

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#### Genuine partnership

I think we're on a cusp and I'm uncertain as to whether we're going to be able to move towards a new paradigm of support, or whether we're going to backslide and get stuck. But I think it's coming together in an exciting way. There's evidence from research, practice, and people's experience around the country that supports a new paradigm of support.

We know how to provide individualized support. We know how to make use of informal social networks. We know how to support people in community life. Whether this practice can become the wave of the future, and whether the new paradigm can take hold, is open to question right now. My greatest hope is that it will. I look at those of us who are parents of children with disabilities who have been fully integrated. These kids will leave high school with more skills and more confidence. If we keep them out of segregated services, and out of social services altogether, even better! They may need personal supports, but we can find creative ways to do that.



Our research shows that every person we've studied who has gained more personal control, had a significant person, at some point, who played a very key role. That significant person may have been someone from a community agency, or may have been someone from other parts of the community. This significant person is like a "mentor", providing a role model of what is possible to do in the community. Or this significant person might provide practical support, or moral support, by "just being there".

## Partners in fun

Sports have become so organized. Providing people the opportunity to come out and have some fun reminds me of the "good old days" when people simply showed up with their bat and ball ready to play. You didn't need three coaches telling you that you were having fun! Unified sports takes the edge off winning and puts greater emphasis on all people getting the chance to play together, without the pressure of being a superstar.

I am a manager of a recreation centre in our town. We have come a long way from the days when the big yellow bus dropped off 30 children with disabilities in front of the centre. Today is different. We no longer offer segregated summer programs. But, of course, there are always new challenges to face.

All our summer activities are offered to children up to the age of 12. But, parents still wanted a place for their teenager to go in the summer. What could we do?

During the winter months, I met with people from the local Association for Community Living. Together, we brainstormed and planned out a way to make it work. They were very resourceful and we worked well together.

We hired Liz, a university student, for four months on a summer employment grant. It was her job to implement our plan. This included helping teenagers pursue employment, recreation and leisure interests.

Liz spent time getting to know each teenager. At times, she and one of the teens would go away from the centre for a walk so that she could learn more about their interests. Sometimes, she met them in their homes.

Liz talked to one of the teenagers, Fred, and his parents. Liz discovered that Fred loves the water and is a good swimmer. Liz suggested Fred help teach in the pool. Fred's parents first reaction was, "Oh no, our son could never teach in the pool!" They hesitated, but they then grew to trust Liz and the idea. Fred had the time of his life assisting the swim instructor in the pool. Now, the parents boast about their son being a pool assistant, and Fred is proud too.

#### Partners in fun

The greatest thing I've learned is not to be afraid to ask people things I don't understand. I have no doubt that next year will be a bit different, a bit better because we have learned from each other.



I had been wondering why so many of the people we support were not more involved in leisure activities in town. Like any good administrator, I took a survey! The number one reason people identified was not money, or transportation. It was simply not having someone to go with. The more I thought about this, the more I realized this was probably true of many people in my city. In fact, I was one. I wanted to start weight training, but didn't know any weight-lifters.

I had an idea and armed with my survey, I approached the Executive Director of the YMCA. I wanted to talk to him about how the YMCA could be involved in linking people who share interests. I had barely made my pitch when he, too, got excited about the possibilities. People were always looking for someone to work out with, or play squash with, or do weights with. The YMCA could offer a service that matched people with similar interests.

The ball started rolling. Together we wrote a proposal, and got money from two different government ministries. We also did some fundraising. We hired a university student to develop and begin the implementation of the idea. A committee was formed from individuals and agencies in the area. When the university student's contract was over, we put an ad in the paper for a volunteer to co-ordinate the service. Response was great and two volunteers now share the responsibilities. Over 100 people from the area have expressed interest in being matched and want everything from a golf partner to having a walking buddy.

Quite frankly, it would have been easier to develop a "recreation program" within my agency. But that would have been a disservice. Not only do people we support benefit from the YMCA's service, but so do seniors, newcomers to town, and anyone else! And yes, I met an experienced weight-lifting partner to motivate me to get off the couch!



I am a member of the Kiwanis Club and a member of the Royal Canadian Legion. I first met some people from the local Association for Community Living at a car wash. It was a joint venture between the A.C.L. and the Kiwanis Club. I met some new people I wanted to get to know better.

While playing darts at the Legion one night, I came up with an idea of having a dart tournament. This tournament would be for Legion members, as well as for people who have a disability. It would be for all of us.

I took this idea to the Legion membership. Some members thought it would never work. People's resistance was the fuel I needed. I started recruiting.

What a great feeling I had the day of the tournament when I saw everyone talking, laughing and cheering together. There was no prize money, or trophies to be won. People came out for the fun of it.

The trick was not to be too well-planned. Names were pulled out of a hat. It was total organized confusion at first, but it was fun, and it allowed people to get know each other. Who cared if someone had to take two steps forward so they could hit the board? What mattered was that people were playing together.

This unified idea had a rippling effect on more community groups in our town. The Kinsmen Club, who in the past had hosted a segregated baseball tournament, decided to host an unified baseball tournament. They invited community teams, and two individuals who access service from the A.C.L. became part of each team. They have hosted this type of ball tournament for the past four years. Later that year, the fire department and A.C.L. jointly hosted an Octoberfest Dance.

The stories are endless. I am glad I didn't give up on the unified idea years ago. Now, Legion members ask me when the next tournament will be!

## There goes the bus,...

Solving problems with getting transportation in rural areas sometimes is a matter of looking beyond the bus.

For years, people living in smaller rural communities were bussed into our city on a daily basis. Our agency wanted to take a closer look at this. It was very expensive providing this transportation service, but our programs had always been based in the city.

We started in the smaller communities by involving people in things that were going on. We asked local people to share their thoughts and ideas on how people could become involved. After all, they knew their community better than anyone else! People who used to spend time riding the bus into a larger centre, ended up getting local jobs, opening bank accounts nearby and getting to know their own neighbours.

Isn't it funny that, because of economic restraints, people have gained far more than they have given up. The agency has been able to reduce its large transportation costs and people have been able to get to know their home town. By working out of people's homes, the focus has changed from programs to individuals. We can't just sit around and talk about the idea of meeting people in their own neighbourhoods. We have to go out and do it!



I have a friend, named Linda, who lives in the same village as I do. Linda used to pick me up once a week in the evening, and we went to a fitness class together at our high school. Through Linda, I got a job at her office. I did not have to be bussed into town everyday like I used to when I went to the workshop. I worked there for one year. I was laid off because there was no more paper-shredding to do.



My support worker helped me find a new part-time job at a retirement home. I meet people on the street I know. I like banking and shopping on my main street too. I do not miss taking the bus everyday. It is good working close to home!

A bus service for our small town was needed. One that would provide an affordable service for all people who are physically challenged, regardless of age, or financial status.

Planning for a bus service began in our town with a small group of representatives from the local hospital, nursing homes, home support services and the Association for Community Living. This group soon grew to include people from local service clubs, the municipal council, churches and the senior centre. Bus line and local taxi service representatives attended meetings and were a valuable asset to the group.

Letters were sent to every church, service club, and organization in our community. We had to tell people what a mobility service was all about and ask for their input.

Once a committee was in place, they kept the dream alive. Fundraising, presentations to councils and on-going public awareness was important. After two years of planning and hard work, we got a mobility bus service for our town. The community is proud of their joint effort, knowing they have achieved something that is beneficial for everyone.

## p.s.

Jumping the gap - more stories and ideas represents the journey we took in our investigation of the challenges and barriers we all encounter as we grow. It is a scrapbook of snapshots that give us a glimpse of the ideas, dreams and acts of courage that have helped people to lead more fulfilling lives. We think these snapshots show that there are creative ways of jumping the gap, and we hope that they offer encouragement and ideas as you progress in your journey.

Comments, ideas, more stories? We welcome audio or video tapes, letters, interpreted or translated thoughts. Please send to:

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